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ORIGINAL ARTICLE

The use of the Family Management Style Framework to evaluate the family management of liver transplantation in adolescence*

A UTILIZAÇÃO DO *FAMILY MANAGEMENT STYLE FRAMEWORK* PARA AVALIAÇÃO DO MANEJO FAMILIAR DO TRANSPLANTE HEPÁTICO NA ADOLESCÊNCIA

LA UTILIZACIÓN DEL *FAMILY MANAGEMENT STYLE FRAMEWORK* PARA EVALUAR EL MANEJO FAMILIAR DEL TRASPLANTE HEPÁTICO EN LA ADOLESCENCIA

Ana Márcia Chiaradia Mendes-Castillo¹, Regina Szyllit Bousso², Caroliny Rossi de Faria Ichikawa³, Luciana Rodrigues Silva⁴

ABSTRACT

Objective: To understand the family management experience of liver transplantation during adolescence based on the *Family Management Style Framework* (FMSF). **Method:** This is a case study that used the FMSF as theoretical framework and the hybrid model of thematic analysis as methodological reference. The case presented is from an adolescent's family that lives in Salvador, Bahia. The data were collected through interviews with the mother and the patient charts analysis. **Results:** The results shows that the family defines the transplantation as threatening and there are divergence between mother and daughter related to the teen's capabilities perception. Facing those discrepancies, the family assumes a protective posture by believing that the teen cannot take care of herself alone. The perceived consequences reflect how much the uncertainty permeates the family environment. **Conclusion:** It is concluded that the use of a model to evaluate the management can help professionals to direct and plan specific interventions.

DESCRIPTORS

Adolescent
Liver transplantation
Family
Pediatric nursing

RESUMO

Objetivo: Conhecer a experiência de manejo familiar do transplante hepático na adolescência à luz do *Family Management Style Framework* (FMSF). **Método:** Trata-se de recorte de um estudo de caso que utilizou o (FMSF) como arcabouço teórico e o modelo híbrido de análise temática como referencial metodológico. O caso apresentado é da família de uma adolescente residente em Salvador, Bahia. Os dados foram coletados por meio de entrevistas com a mãe e análise de prontuário. **Resultados:** Os resultados mostram que a família define o transplante como ameaçador e que há divergência entre mãe e filha acerca da percepção das capacidades da adolescente. Diante de tais discrepâncias, a família assume postura protetora, por acreditar que a adolescente não sabe se cuidar sozinha. As consequências percebidas refletem o quanto a incerteza permeia o cotidiano familiar. **Conclusão:** Conclui-se que a utilização do modelo na avaliação de manejo pode ajudar os profissionais no direcionamento e no planejamento de intervenções específicas.

DESCRIPTORES

Adolescente
Transplante de fígado
Família
Enfermagem pediátrica

RESUMEN

Objetivo: Conocer la experiencia del manejo familiar en el trasplante hepático en la adolescencia a la luz del *Family Management Style Framework* (FMSF). **Método:** Estudio de caso, que utilizó el Family Management Style Framework como marco teórico y el modelo híbrido de análisis temático como referencial metodológico. El caso presentado es de la familia de una adolescente trasplantada residente en Salvador, Bahia. Los datos fueron recogidos por medios de entrevistas con la madre y el análisis de registros médicos. **Resultados:** Los resultados muestran que la familia define el trasplante como una amenaza y que existe divergencia entre la madre e hija acerca de la percepción de las capacidades de la adolescente. Dadas estas discrepancias, la familia asume una postura protectora al creer que la adolescente no sabe cuidar de sí misma. Las consecuencias percibidas reflejan cuánta incertidumbre impregna la cotidianeidad familiar. **Conclusión:** El uso de modelos para evaluar puede ayudar a los profesionales en la planificación de intervenciones específicas.

DESCRIPTORES

Adolescente
Trasplante de hígado
Familia
Enfermería pediátrica

* Extracted from the thesis "Manejo familiar no transplante hepático da criança", Nursing School, Universidade de São Paulo, 2011. ¹ Post Doctoral Fellow (CNPq), Nursing School, Universidade de São Paulo, São Paulo, SP, Brazil. amcm@usp.br ² Associate Professor, Maternal-Infant and Psychiatric Nursing Department, Nursing School, Universidade de São Paulo, São Paulo, SP, Brazil. ³ Master of Sciences, Nursing School, Universidade de São Paulo, São Paulo, SP, Brazil. ⁴ Pediatrics Head Professor and Chief of Pediatric Gastroenterology and Hepatology Services, Universidade Federal da Bahia, Salvador, BA, Brazil.

INTRODUCTION

Organ transplantation is the surgical intervention recommended for the treatment of vital organs progressive dysfunctions, prolonging survival and enhancing the quality of life from those patients⁽¹⁾.

In 2013, 7,649 organ transplantations were made in the country. From those, 1,723 were liver transplantations, an increase of more than 100% in comparison to 2003, when 816 were conducted⁽²⁾. From the liver transplantations in 2013, 204 were in patients younger than 18 years old⁽³⁾, indicating a discrete increase on the past five years, considering that in 2008, 197 transplantations from the same modality were made in this age group.

The increase in transplantations in children and adolescents worldwide boosted studies regarding the psychosocial impact that the procedure plays in the child, adolescent and in their family⁽³⁻⁴⁾. Considering the child and adolescent experience from the perspective of those who lived the hepatic transplantation, the literature affirms that two crisis phases exist. Those are represented by *knowing the need of the transplantation and receiving the transplant*, both marked by the family imbalance due to the adaptations that are more intense in those periods; and two phases marked by relative constancy and stability, although still exposed to risks and uncertainties, which are waiting for the transplantation and living with it⁽³⁻⁴⁾. The family can and should be helped in this process during all phases – and not only during crisis moments, when they normally receive more attention⁽⁴⁻⁶⁾.

The youth period according to the Brazilian Child and Adolescence Statue is between 12 to 18 years old⁽⁷⁾ and is characterized by deep physical, psychic and social changes that affect behavior. Those are potentiated in adolescents with serious illness that need transplantation. This age has constant changes since the pre-pubertal and pubertal period and goes until the post-pubertal period. Those changes influence significantly the adherence to the treatment, self-image, facing the age challenges, the illness and the procedure, the harmony between their peers and family; therefore it needs more investigation⁽⁸⁾.

Transplantation requires adaptations and adjustments for the rest of life; the health team should see the family as a unit of care – and not only the patient. To assist them in this experience, it is important that the professional understands how the family responds in their routine to the care of their transplanted child or adolescent. By doing so, the team can have subsidies to direct specific interventions to the reality and demands of each family during not only during crisis but also the stable moments during the disease process.

Family Management Style Framework (FMSF)

The family management can be defined as *the role of the family while actively responding to disease and different situations in health care*⁽⁹⁾. The FMSF was built from a wide literature review, developed to identify the key aspects of how the family as a unit responds to the disease of one of their members⁽⁹⁻¹⁰⁾. It involves three main dimensions: the definition of the situation, the management behavior and the perceived consequences. The definition of the situation is how the family perceives the sick person and the disease. The management behaviors include the principles that are the basis for the development of a routine to conduct the disease in the family. The perceived consequences are defined as the real or expected results that shape behavior and, consequently affect the definition of the situation⁽¹⁰⁾.

The FMSF has been used to study chronic illness situations in different contexts⁽¹¹⁻¹³⁾. In Brazil, there are already few FMSF studies in the pediatric oncology context⁽¹⁴⁾ and with palliative care⁽¹⁵⁾. It was not found national or international studies that used FMSF when the chronic patient is an adolescent. The international literature points out the tendency to an important family unbalance when the adolescents need health care due to a chronic condition, because of the resistance that it can offer when following a treatment regimen⁽⁸⁾.

Facing this scenario in which the relevance of knowing how the family defines the situation and manages the family life in different contexts of the disease grows internationally, and considering the need for new investigations in different cultures and stages of the vital cycle; the present study aims to explore the family management experience in the context of the transplantation during adolescence. The objective is to investigate the family management experience of one transplanted adolescent using the FMSF⁽¹⁰⁾.

METHOD

This is a qualitative case study cut from a primary research that aimed to know the family management when a child is submitted to a liver transplantation. A case study is (...) *an empiric investigation that looks at a contemporary phenomenon inside its context, especially when the limits between the phenomenon and the context are not clearly defined*⁽¹⁶⁾. It was opted to use the case study because it allows the phenomenon understanding – *the management experience* - inside its context – *the family life and the disease trajectory*. For the primary study, it was conducted four case studies of families that had a child who received a liver transplantation for at least one year and was receiving post-surgery accompaniment in the gastro pediatric ambulatory in a university hospital in Salvador, Bahia.

This study presents the fourth case, which is from a family of an adolescent, whose fictitious name is Alice. In the previous three cases, it was possible to perceive that the families were afraid of the transition from childhood to adolescence because they believed their children wouldn't be able to assume their own care. This led us to the methodological option to focus on understanding and analyzing one family that already dealt with the transplantation during adolescence. The medical team indicated Alice's family, who was the oldest patient at the ambulatory.

Alice, 16 years old during the data collection, is the daughter of E., 42 (mother), and J., 50 (father). She had received the liver transplantation in May 2009 from a deceased donator. She has a brother, Er., 17 and two sisters, Er., 19, and M., 22. The parents have been divorced for 15 years and Alice keeps close contact with the father but he does not participate much in the care. In the same year that they divorced, E. met J., 49, with whom she refers to have a stable relationship. Alice lives in Salvador with her mother, the stepfather who is a waiter and one of her nephews, Eli, 3 years old. The mother used to work as a housekeeper but nowadays she exclusively dedicates herself to Alice's care.

The study was approved by the Ethics in Research Committee (protocol CEP 754/2008). Alice's mother was the one who participated in the study because she is the main caregiver and used to accompany her in the appointments. She freely consented to participate signing the free and informed consent form.

As recommended by the case study design, it was used multiple points and strategies for data collection. This approach is fundamental in case studies to guarantee the depth needed in the study, the case insertion in its context and also for more credibility of the results⁽¹⁶⁾.

It was conducted three data collection moments with the participant:

- **First moment:** after obtaining the consent for inclusion in the research, the first moment was designed to collect identification data and a to conduct a first open interview, aiming to understand the transplantation experience and the family life in its broader context.
- **Second moment:** designed for a semi structured interview with questions based on FMSF⁽¹⁰⁾, with the purpose to understand the family management.
- **Third moment:** designed to finish the case, to clarify doubts and to validate the gathered information.

The meetings were set up at the most convenient dates for the participant, audio recorded and fully transcribed.

Between the first and second moments there was a data collection in the medical records to complement and to deepen the knowledge in the case and to give additional aids to better direct the interview and eventual needed clarifications.

The data analysis was guided by the thematic analysis that is a way to recognize patterns inside the data, in which the emerged themes are pooled into categories⁽¹⁷⁾. In the thematic analysis, there are different approaches, one that is deductive, based in templates previously determined, and there is the inductive approach, guided by the data. In this study, the chosen method was a hybrid thematic analysis model which includes the deductive and the inductive approaches⁽¹⁷⁾.

This choice allowed the given guidelines in the adopted theoretical model to be integrated to the deductive thematic analysis process and allowed the appearance of direct themes from the data using inductive codification. The thematic analysis hybrid model has been used and recommended in nursing research⁽¹⁷⁾.

RESULTS

The presentation of Alice's case

a) The adolescent's disease trajectory in the family

Alice was born in September 6th, 1994. The first disease symptoms appeared in December, 1999, abruptly: anasarca and ascites that were investigated without conclusive results. After few hospitalization days and drug therapy the case reversed and she was discharged. Since then, her mother relates that the anasarca episodes were constant, needing frequent hospitalization for drug therapy to reverse it.

Only in June of 2006 it was found the existing deficiency of alpha-1-antitrypsin and the transplantation was indicated as the only viable therapeutic measure. She was conducted to São Paulo and a journey against the time has started: the waiting period for a deceased donator generated anguish and uncertainty in the family.

During the waiting time, Alice had episodes of portal hypertension and hematemesis that were treated in the hospital in Salvador. In January of 2008, she needed to be admitted to the ICU because of bronchial pneumonia, pneumothorax and bleeding esophageal varices. The mother had to stop working at this time because she could not conciliate the trips to São Paulo with the eventual job that she used to do.

In May of 2009, Alice was weak with important ascites unable to do physical efforts- even the small ones. After a week in São Paulo and with all the exams done, she and her mother were getting ready to go back to Salvador when they received a call from the hospital informing about the deceased donator. The transplantation was done on the same day, May 26th, 2009, successfully. The recovery was considered satisfactory but her mother was not fully prepared to deal with it, as she did not know many of the common post-surgery procedures: she was shocked to know about the need to stay in the ICU and only with time she learned what she should expect from then on.

After the three months when the post-transplantation accompaniment was more intense in São Paulo, Alice and the mother went back to Bahia. The mother was really happy with the transplantation, especially because after it the family got to socialize more frequently again. For Alice, the transplantation allowed her to live life with more energy and in more similarity to the other teens her age.

Alice is asymptomatic since she returned to Bahia, she does the periodic accompaniment in São Paulo, and she went back to school normally and did not have intercurrents. Her mother did not return to work and says that she does not believe it is possible due to Alice's care needs.

b) The family management experience

Although the family perceives very positive changes with Alice's transplantation, there is a great effort to keep the transplantation care under control; they believe that the patient has a severe condition and even though she can develop activities compatible with her age, she will always have a lower quality of life comparing to other adolescents.

The family perspective is different from the one Alice has about herself. She sees herself as a healthy teen, capable of doing everything that other people her age does. This perspective is not shared with her mother and her stepfather who believe that even though she can have a life called normal, there are always deprivations due to the disease and those need to be addressed. This difference in perspectives brings conflicts in the transplantation management care.

(...) I have to watch her close because she says: *Ah, I did the transplantation, I can do everything, I am normal...* And I know it is not like this... if I let it go, everything can come back, she can get worse and can lose (the transplantation). So, I tell her: *Look, you are not a perfect person, you are not a normal person, and you are not the same as you used to be before having the disease. So, there are things that you have to watch...*

In the beginning of the disease trajectory, the lack of knowledge about the transplantation gave the wrong perspective about the disease progression to the family. For them, the transplantation was the cure for Alice. As the disease progressed, the family started to realize, especially with other families of transplanted kids and teens, the changes that the transplantation experience would make in their lives. They understood the implications and care needed and nowadays, they believe that the disease is a severe condition with an uncertain route that requires a great investment.

I did not know anybody with transplantation, now I know a lot of people, but I didn't before. Today I know that the environment is really different. But not before.

One year after the transplantation, Alice's family fights against the fear of not caring of her as she needs. The medical recommendations are listened carefully and fol-

lowed strictly in terms of prohibitions and restrictions that are imposed. The mother feels overwhelmed, unable to go back to work although the daughter has already completed 16 years old, due to the definition that she does of the teen. She sees the transplantation as something really hard to accommodate to the other family routines because it demands too much time and care and, it is upon her the biggest and heaviest responsibility.

The different perspectives of Alice and the rest of the family regarding the transplantation meaning causes conflicts between them and results in the belief that she still did not acknowledge the dimension of her health problem – and it is up to the mother to keep and protect her from the activities that were even allowed by the medical team. For E., it is her first responsibility to assume Alice's care.

I needed to work, but I cannot work. I can go to do a cleaning appointment, basic things, but for the daily basis I know I have to be there with her.

Alice's parents adopted an overprotective posture and do not allow her to develop activities compatible with her age because they fear that something can happen. They believe that they need to constantly alert her about the dangers that she is exposed to, to protect her from activities that they believe it is threatening and to control with caution the activities in which she is involved.

I try to scare her...like... sometimes I just tell her not to abuse, I tell her to remember that she is not such a normal person like me or you. But a lot of things she can do already.

Considering the present, the family focuses on the positive results reached on the past year since the transplantation. The positive results encourage and help to perceive the present as an opportunity to go back to activities that before were impossible due to the disease, like celebrating special dates, leisure activities and more free time.

Today I know how it is to spend Christmas at home again, what is like to spend São João at home, because before, with her, I forgot, it was only at the hospital, only at the hospital!

But for the mother, the transplantation caused many changes in the family life and demands a big investment of their time. The belief that it is the mother's role to assume the daughter's care makes her to see herself without the possibility to start again a professional activity.

(...) I go back to this topic, the topic of working, I can't work! I need to work...and I cannot have a stable job and I see that this interferes even for her, because ends up that we do not have much condition to give her things, to do things for her, one or another thing that she likes that we cannot give it to her.

Living her adolescence, Alice faces problems characterized from this phase at the same time that she faces the transplantation consequences in her life and self-image. Before the surgery, she felt ashamed of her appear-

ance because of the liver disease and she felt discriminated at school because of it. Today, with the diminished abdominal volume and by reaching normal features, she perceives herself more secure, less vulnerable, happier and more at ease to dress and have relationships. On the other hand, the scar in her abdomen makes her feel embarrassed and prevents her from wearing clothes that exposes any part of her body that can make her feel different from the other teens.

(...) She is embarrassed of her surgery. She does not wear a top if it is a little shorter or if it is a silly transparency even; no, no, she does not wear it, it has to cover her whole belly. But, I think it is the only thing that makes her a little different.

The different perspectives from Alice and the rest of the family about the disease severity do not only model the family posture to deal with the present, but also fulfills the future days with doubts. The family fears that Alice's stubbornness of doing activities that they believe to be impossible will persist for her whole adolescence and also when she is a youth, and that this will bring negative consequences to her health. They fear that she does not have the needed responsibility and is not mature enough to recognize her fragilities and the care that she needs to have with herself.

She is too stubborn. Then I am afraid...like...because I don't know if she will be capable...I don't know if she will be the kind of girl that will understand herself and be able to look at something and say: *No, this I can't.* (...) I get afraid because she is stubborn, but I hope and expect that if she keeps stubborn, that this lasts little, I don't know, until 20, 21 years old and then she will stop, think and say: *Look I can't do this because I am like that and this will not be good for me.* I hope that she will be like that one day, without me needing to watch her all the time, you know? But I don't know...When this comes, I am not really confident!

The supposed stubbornness of Alice causes the sensation of losing control in the family and makes their members more insecure and uncertain regarding the future. Alice's adolescence is lived by the family as a threat to her health and the family hesitates to make the rules more flexible and to allow her to acquire more autonomy fearing that it will bring harms to her health. Fearful, they incorporate vigilance to their everyday life and they have difficulties to loosen their patterns and conducts.

DISCUSSION

It is unequivocal that a disease in the family alters the balance as a whole in the family system. The nurse should know the way that the family tries to reorganize and manage the demands caused by the disease, in order to help achieve the balance. The use of the family management framework⁽¹⁰⁾ provides a deep understanding of the experience lived by the family.

In this study, it was possible to notice that the use of FMSF⁽¹⁰⁾ enabled the organized comprehension surrounding the transplantation family management in adolescents, like in other chronic disease contexts. Besides that, it allows to think in specific interventions for the family, focused in their real needs.

In accordance with the Model, the way that the family manages the experience of having one of their members with a chronic condition is determined mostly by the definition of the situation⁽¹⁰⁾. In Alice's case, this definition plays a big influence on her behaviors. Therefore, it is pretended to discuss the components of this dimension in Alice's family experience, enlightened by the relevant literature, and to suggest paths for interventions according to the presented demands.

For Alice's family, the perception of her being still fragile and not being able to do activities that the other teens can, is associated with the vision that she is stubborn and immature – by disagreeing frequently with the mother's opinion, generate conflicts and difficulties in the family to get organized and to establish routine and safety to manage the care. Studies have been proving that the families that tend to define the sick child or adolescent focusing in their weaknesses and hardships, will present lower family quality of life. Studies suggest that this definition can even shorten the survival time of the transplanted patient^(3,18).

Concerning the beliefs that define the view of the illness, there is evidence that it tends to modify throughout the time⁽¹⁹⁾. If before the family is scared and frightened, believing that the disease is severe and scary, with time, the family members acquire knowledge that challenge their previous beliefs and give place to new values and definitions.

The disease development over time gives opportunity to the family to interact with different elements in the experience and to look for alternatives and strategies to face it and live with the disease⁽¹⁹⁾. Other studies also identified that the time in the chronic disease context is an ally for families to acquire the competencies and abilities, once the transformation on the illness view can result in more control and certainty in managing care^(5,12-13,20).

Time can provide the opportunity to the professionals to challenge the family members and to rethink and reformulate their system of beliefs about the disease, as their abilities to manage the care. To recognize it as an ally can make the professionals become more sensitized when looking at the families that deal with this experience for less time, and to be more able to provide resources that the families themselves indicate as relevant. The conversations with families that live the same situation contribute for that, so much as the daily contact with the team and the personal experience by different moments in the disease trajectory.

Therefore, in Alice's family, it was exactly the acquisition of knowledge over time that brought to the family members the increased uncertainty and the belief that the transplantation is a severe and unpredictable condition. As the family had wrong information at the beginning of the disease trajectory, it was believed that the transplantation would be an alternative, and consequently, the definitive cure. When discovering later that it would not be like that, the suffering was intensified when the unknown path was perceived, and they realized that the demands and obstacles to overcome were bigger than expected.

In families with chronic patients, the acquired knowledge by the *know that* should be complemented by *know how* for them to have abilities to manage the care⁽²¹⁾. In the case of Alice's family members, to *know that* existed care for the rest of her life left them fearful by not having acquired the *know how* to care and what to expect from then on.

The need of information is one of the main demands from the families with chronic disease patients and needs intervention from the nursing staff⁽²²⁾. The literature points that the information acquisition gives the parents the needed knowledge to be capable of caregiving: they can reacquire control of the situation, they feel more able to request the partnership with the health team in decision making regarding the treatment. The awareness, the capability and the nurse professionals training are essential, so that each family is assessed and their information needs are recognized, generating a plan of information sharing that is adequate to each case in terms of content and language.

Living with the transplant requires adaptations from the families also in relation to how they define the normality in their lives, as in the context of the other chronic diseases. In this study, Alice's family was able to say that lived a normal life from the moment that they redefined the concept of normality facing the new reality that they experimented. Although life did not go back to what it used to be, the family had some control over the care, which led to the incorporation of it to the routine and to reformulate the experience of living with normality.

But this control is fragile. When analyzing the family dynamics in the liver transplantation of kids and teens, one study identified factors that have the potential to cause uncertainty to the families in this situation⁽⁵⁾. Within them, there are the routine medical consultations, the minimal clinical variations in the child's health (or common symptoms), and the changes in the therapeutic regimen, the prognostic evidences or negative results in other children, besides the changes in the development stages of children. The nursing team should be aware of the threats in the sense of families' control, which sometimes are underestimated by the professionals, for being considered minimal or usual things. The evaluation and

continuing therapeutic communication with the families facilitate the opening for dialogue and the planning of preventive measures, so that the uncertainty does not threaten the family system autonomy.

Another important concept to be discussed in this case is the transition, that is, the way people respond to change along time⁽²³⁾. The individuals go through a transition period when need to adapt to new situations or circumstances aiming to incorporate changes in their lives. The child and adolescent transition to adulthood is worrying regarding the chronic condition that demands to follow a treatment regimen.

This transition process consists of two different and relevant phases to all children that have a chronic condition^(8,23). At first, during the adolescence phase, the treatment regimen coordination and the responsibility for decision making start to be transferred from parents to the patient. Secondly, in some moment, adolescents and young adults are transferred from pediatric units to others that provide health care to adults. Those steps need to be cautiously planned because the teens can stop following the treatment regimen when they acquire more control of the decisions.

The parents frequently feel fearful about their child capacity when entering the adolescence to adhere to the treatment with the same rigor and zeal as they used to do. Some research indicates that the transplanted adolescents tend to stop taking their medication and to follow the prescribed treatment; the most contributing factors to it are related to the unpleasant taste of medications; to the constant frequency and rigorous times to administer it, to the desire to be like the other teens, besides family problems, depression and rebellion^(18,24).

The care responsibility transition seems to be a challenge to the adolescent, to the family and also to the healthcare team, as the barriers can lead this teen to stop following the treatment if not identified and worked out by specific strategies of cognitive and behavioral interventions⁽²⁴⁾. To Alice, for example, the difficulty in following imposed restrictions is related to the perception that she has of herself, that considers (and desires) to be normal like the other teens of her age. For her mother, the daughter's attitude is seen as stubbornness and immaturity. To develop strategies with the multi professional team that incentives mother and daughter to share their perceptions and experiences can help them to understand each other perspective and to provide aids to the team as an objective to direct them to a converging path.

CONCLUSION

The case presents the family management experience of a transplanted adolescent. Based on the family definitions of the teen, the disease, her abilities to manage the

care and support received, their behavior is shaped to incorporate the transplantation to the family routine.

In Alice's family, the difference of perspective between the parents and the adolescent bring consequences in relation to the way that all react facing the challenge of living with the transplantation. The pediatric transition to adulthood requires special care, it should be thought along with the family and the team as soon as possible

to provide a transition where the patients feel completely motivated to assume their own care.

The identification of components and the dimensions proposed by the FMSF are useful in the professional practice. The use of this theoretical model in assessing the family management can help the health professionals to plan specific interventions to each family – and should be encouraged.

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